



King's Research Portal

DOI:

[10.1007/s11892-015-0660-z](https://doi.org/10.1007/s11892-015-0660-z)

Document Version

Early version, also known as pre-print

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Sturt, J., Dennick, K., Due-Christensen, M., & McCarthy, K. (2015). The detection and management of diabetes distress in people with type 1 diabetes. *Current Diabetes Reports*, 15(11), 101. <https://doi.org/10.1007/s11892-015-0660-z>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Title: The detection and management of Diabetes Distress in people with Type 1 Diabetes

***Jackie Sturt PhD, BA (hons), RN, RMN ¹**

jackie.sturt@ckl.ac.uk

+44 (0)20 7848 3108

Kathryn Dennick MSc, PhD ¹

kathryn.dennick@kcl.ac.uk

+44 (0)7929528584

Mette Due-Christensen MSc, RN ^{1 3}

mette.due-christensen@kcl.ac.uk

mtdc@steno.dk

Kate McCarthy PhD, RN ²

kate.mccarthy@uhcw.nhs.uk

+44 (0)24 7696 4000

¹ Florence Nightingale Faculty of Nursing and Midwifery, King's College London. James Clerk Maxwell Building, 57 Waterloo Rd, London. *SE18WA. UK

² University Hospitals of Coventry and Warwickshire, Clifford Bridge Road, Coventry. UK

³ Steno Diabetes Centre, Health Promotion Research, Niels Steensens Vej 8, 2820 Gentofte. Denmark

*Corresponding author

Key words:

Diabetes distress; type 1; review; interventions; correlation

Abbreviations used: DD Diabetes distress, RCT Randomised Controlled Trial, HbA1c Glycated Haemoglobin, DAFNE Dose Adjustment For Normal Eating, DSME Diabetes Self-Management Education, PAID Problem Areas In Diabetes Scale, DDS Diabetes Distress Scale, SD Standard Deviation, CGM Continuous Glucose Monitoring, CBT Cognitive Behaviour Therapy.

Words 4,198

Abstract

Diabetes distress (DD) represents a significant clinical burden in which levels of DD are related to both HbA1c and some self-management behaviours. DD is related to, but different from, depression. Differences in DD experienced in people with type 1 and type 2 have been observed. Commonly measured by the Problem Areas in Diabetes Scale and the Diabetes Distress Scale, rates of elevated DD in research study participants range 20-30%. Risk factors for elevated DD in type 1 are a longer duration of diabetes, severe hypoglycaemia, younger age and being female. A systematic review of intervention studies assessing DD identified eight RCTs and nine pre-post design studies. Only three studies targeted DD with the intervention. Intervention types were diabetes self-management education (DSME); psychologically informed self-management and; devices. DSME pre-post studies, namely the DAFNE programme (Dose Adjustment For Normal Eating), produced more consistent improvements in DD and HbA1c at follow up. Psychologically informed self-management were more heterogeneous but several RCTs were effective in reducing DD. Group interventions offered the greatest benefits across intervention designs.

Introduction

Diabetes Distress (DD) has been increasingly recognised in research practice for two decades but has only recently achieved a sharper focus in clinical practice. Much of the research attention has been in type 2 diabetes. This paper is the first to review the evidence for DD in type 1 diabetes. We present a definition of DD and consider its associations with the important diabetes end points of glycaemic control, self-management behaviours and depression. Rates of elevated DD in research populations and the relative merits of screening for DD are considered. We present a systematic review of interventions for managing DD in clinical environments. The paper concludes with a number of research priorities to further our understanding of DD in people with type 1 diabetes.

Definition of Diabetes Distress

Diabetes distress (DD) reflects a range of different emotional response to patient's perceptions of health threats balanced against an appraisal of available coping resources, and it is content-related necessitating a focus on distinguishing among the different sources of distress in diabetes so that specific interventions can be initiated (1). Esbitt et al (2) explain that DD is "predicated on a variety of medical, contextual and individual factors, not on the presence of a psychiatric condition" (p35).

Manifestation of Diabetes Distress in type 1 and type 2 diabetes

Some studies suggest that DD does not discriminate by diabetes type (3, 4), but it cannot be presumed that emotional problems are similarly experienced, and have the same consequences in Type 1 and 2 diabetes. Indeed, the most commonly reported emotional problems in Type 1 diabetes relate to hypoglycaemia and complications; worry about the future and complications, feeling burnt out/overwhelmed, and worrying about low blood sugar reactions (5-7), whereas in Type 2 diabetes emotional distress relates more to goal setting and food restrictions (7). Qualitative work confirms stressors unique to Type 1 diabetes; realisation of the possible consequences of previously poor self-management as adolescents, apprehension about pregnancy, anxiety about being perceived to have Type 2 diabetes, frustration competing for resources with Type 2 diabetes and a great many concerns specific to insulin use (8, 9). Our own case note documentary analysis observed differences in the manifestation of DD in the two populations (10). Type 1 case notes revealed core issues resulting in elevated DD being lack of diabetes control and fear of associated complications with common behavioural manifestations resulting in the maintenance of high blood glucose levels; low levels of blood glucose monitoring and medication non-concordance. In contrast, type 2 case notes indicated; Isolation, work related issues, family demands, obesity and lack of knowledge. We found some diabetes distress themes reported in both type 1 and 2; neuropathic pain, fear of complications, fear of hypoglycaemia, poor sleep, loss of medication or diet control, dietary control (calorie restriction in type 2 and carbohydrate counting in type 1), loss of independence and lack of support. It is clear from this early understanding of differences in DD that different management foci may be required.

Diabetes Distress related to depression

Previous psychological research in diabetes has focussed on depression, but it is now apparent that there has been a lack of clarity and precision in the measurement of depression in diabetes (1, 11). Depression and DD are strongly associated in Type 2 (12) but also in Type 1 diabetes (9, 13). Prospective research in mixed diabetes samples suggests a bidirectional association (7, 14, 15), with

emerging evidence in Type 1 diabetes that DD exacerbates the risk of incident depressive symptoms two fold (16). Depression assessment constitutes a symptom count irrespective of cause or context, whereas DD reflects an emotional response to the adversity associated with living with and managing diabetes (11), and Fisher et al (1) explain that “exclusively symptom based depression scores most likely capture the affect component of DD” (p769). Qualitative studies suggest that where a person with type 1 diabetes has depression it is often related to their experience of diabetes (9, 17). Fisher et al (1) explain that emotional distress in diabetes should be considered “a single continuous dimension that has two primary characteristics: content and severity; that the primary content of emotional distress among these individuals include diabetes, it’s management, other life stresses and other contributors (e.g. personal characteristics, life history and genetics)” (p764). There is therefore a need to move beyond conceptualising ‘distress’ in diabetes as diagnosable depression and recognise the impact of disease-related factors on emotional well-being (18).

Measurement of Diabetes Distress

The concept of DD emerged alongside the development of the Problem Areas in Diabetes (PAID) scale (19), with later revisions resulting in the Diabetes Distress Scale (DDS) (20). We recently completed work to distinguish between measures of DD (unpublished data). The PAID was developed with a sample predominantly comprised of people with Type 1 diabetes (19), and the psychometric properties of the DDS for adults with Type 1 diabetes has recently been established (21). These measures have been extensively psychometrically evaluated in type 1 and type 2 diabetes (22), parents (23), adolescents (24) and languages and cultures (21, 25, 26). Qualitative work, however, suggests additional aspects of DD important in Type 1 diabetes are omitted from these measures; fear of hypoglycaemia, problems maintaining a normal work-life balance, fatigue (21), and guilt about social burden, for example the possibility of an emergency (9). As a result of these concerns, the Type 1 Diabetes Distress Scale (DDS-T1) was recently developed (27). The DDS and DDS-T1 are comprised of empirically established sub-scales such as the DDS emotional burden and regimen distress sub-scales (20, 27) and have been employed in research studies (28). Short forms and screeners such as the DDS2 and PAID-5 are also available (3, 29-31).

Relationship to endpoints in Type 1 diabetes

HbA1c

Cross-sectional evidence has consistently shown that any one point in time someone with elevated DD is likely also to have high HbA1c in type 1 diabetes (5, 32). However, DD is not prospectively

related to HbA1c when baseline HbA1c is controlled for; someone experiencing higher DD is not apparently at risk of increasing their HbA1c, or indeed developing high HbA1c, as a result of this initial distress, at follow up. (33) (34) However, some evidence in type 1 diabetes suggests that intervention related changes in DD are associated with changes in HbA1c with a marginally significant trend suggesting these concurrent changes are related although causality cannot be inferred (35). This mirrors findings in Type 2 diabetes (36). Furthermore, Weinger et al (2001) found that high baseline DD hampers improvement in HbA1 suggesting that interventions must address existing DD to evidence improvement in clinical outcomes(35). Some unpublished studies have failed to support an association between DD and HbA1c in Type 1 diabetes though (37, 38), suggesting a complex relationship between these variables that requires further exploration. DD has been shown to explain the relationship between depressive symptoms and HbA1c (3, 39). This mirrors evidence in mixed and Type 2 diabetes samples (7, 40-42).

Self-management behaviours

Cross-sectional evidence suggests that DD impacts self-management behaviors in Type 1 diabetes, namely less physical activity, poorer diet (21) and eating styles that are associated with overeating and high HbA1c (6) and insulin restriction (43, 44) . Other studies suggest DD is not associated with self-monitoring of blood glucose, smoking and alcohol consumption, and that its association with physical activity may be explained by more general emotional distress (13). This evidence base is very much underdeveloped at present, though. Martyn-Nemeth (2014) identified that there may be a level at which DD becomes immobilising resulting in fewer behaviours to avoid hypoglycaemia at very high levels of DD (6). Sturt et al (2015b) found that in type 1 and 2, people with elevated diabetes distress alongside psychological morbidity, including low mood, were unable to convert strongly desired self-care intentions into actions (10). Conversely, individuals with diabetes distress *only* were more successful at initiating self-care behaviours' and developing self-efficacy indicating that DD alone is easier to target (10). Other mixed type and type 2 only studies have found that it is the co-morbidity of DD and depression that is associated with the highest levels of HbA1c (45-47). This suggests that when you have both DD and depression it impacts the most on self-management behaviours that aim to control glycaemia and becomes most difficult to resolve.

Regimen distress and diabetes endpoints

Research in Type 1 diabetes has explicitly demonstrated that the element of DD that appears to drive the aforementioned associations with HbA1c, and self-management behaviour, is regimen distress (6, 21, 33, 35, 39, 48). The smallest change in regimen distress which can be subjectively

realised by individuals, 0.5 SD change, is associated with a difference of 7 mmol/mol (0.6%) in HbA1c (39).

Thresholds for, and rates of, clinically relevant DD

No epidemiological studies have assessed for DD therefore all data on degrees of DD amongst people with diabetes and proportions of people with diabetes experiencing elevated DD are derived from interventional or cross sectional research studies which in itself results in a likely population bias. Investigators have used a range of thresholds across type 1 and 2 populations to define elevated DD from PAID scores in the low 30s (49, 50) to 45-50 (51, 52). Studies in Type 1 diabetes have endeavoured to establish the curvilinear relationship which has been observed in type 2 between DD and HbA1c, diet and physical activity (53). In Type 2 diabetes the shape of these relationships indicated thresholds for low (a DDS mean score of 1-2), moderate (a DDS mean score of 2-3) and high (a DDS mean score over 3) clinically relevant DD; each successive increase in DD is associated with a 0.5 SD increase in HbA1c or decrease in self-management behaviour. However, the studies in Type 1 diabetes found no evidence of these relationships (21, 39), suggesting that emotional problems have different implications in Type 1 and 2 diabetes and that in Type 1 diabetes interventions can be applied, and will be effective, at any non-zero level of DD (21).

The majority of empirical studies to date have used thresholds of PAID ≥ 40 and a DDS >3 to indicate elevated DD (28). In scoping the literature we identified 11 studies which have reported proportions of type 1 populations with elevated DD (2, 21, 38, 47, 54-60). These proportions range from 8% (57) to 65% (2). Nearly half of these studies (combined population of 875 participants) reported proportions of participants with elevated DD of between 17-31% (38, 47, 58, 60, 61). The mean ages of participants in these studies was between 37-52 yrs with the largest study reporting on 466 participants, mean age 37yrs, finding 28% to have elevated DD (47). A large international study with 8,500 participants (DAWN 2 study), of which 16% were type 1, found 44.6 % of the study population to have elevated DD on the PAID 5 (62). The evidence suggest that 20-30% of people with type 1 diabetes will be experiencing elevated diabetes distress that will be affecting their self-management behaviours and their glycaemic control. Given that the majority of the evidence we have observed did not have psychological morbidity inclusion criteria and that those with psychological morbidity would be regarded as hard to reach and unlikely to volunteer for research participation, it is likely that this is an underestimation of the true picture.

Specifically in Type 1 diabetes, risk factors for DD include a longer duration of diabetes (21, 63) and episodes of severe hypoglycaemia (5). Age is also negatively correlated with DD (5, 21) with adolescents and younger adults endorsing feeling scared when thinking about living with diabetes, guilty about getting off track with diabetes management, unsatisfied with their diabetes physician, discouraged with their diabetes routine, and experiencing uncomfortable interactions about diabetes with family/friends as more serious concerns than do older adults with Type 1 diabetes (5). DD is greater for women than men (21, 49, 63, 64) with women also exhibiting higher prevalence of subcutaneous insulin infusion, greater self-monitoring of blood glucose and a higher level of motivation yet no difference in HbA1c level perhaps suggesting that greater effort in maintaining HbA1c is at the cost of higher DD (49). Interestingly women, but not men, with Type 1 diabetes have been shown to experience greater DD when they live without a partner, an effect that is partly explained by social support albeit the precise mechanisms of this association have yet to be established (65).

The pros and cons of screening

Routine psychosocial screening for DD and depression has been recommended at key time points in the care pathway, including; diagnosis, annual reviews, in-patient episodes, new complications, and when issues of glycaemic control, self-management and quality of life arise (66). The incorporation of psychosocial assessment and treatment into routine care, through a collaborative team approach, is recommended (11, 66, 67), however, no screening studies involving only the assessment for DD have been conducted solely in type 1 populations. These recommendations assume firstly that the screening process is effective in detecting vulnerable people, secondly that psychosocial care pathways are routinely available and thirdly that these services are acceptable to patients. Fleer (2013) found in a mixed type 1/type 2 sample that only 36 of the 104 participants found to have elevated DD accepted further referral to psychological services (57). With limited resources, Byrne et al (2012) argue that individuals likely to benefit the most should be targeted for intervention, including those with higher diabetes distress at baseline (50). Ironically, the hard to reach group that don't respond to screening, have the most to benefit from it (57). Conflicting evidence exists concerning diabetes healthcare professionals capacity to clinically detect diabetes distress. Pouwer et al (2006) report under detection of DD by diabetes nurse specialists in 75% of patients with established distress (68). Conversely, Sturt et al (2015a) found that clinicians were able to detect elevated DD during their routine consultations (10). Clinicians may not seek to uncover DD if local psychological care services and care pathways don't exist for the management of elevated DD. Fleer et al (2013) suggested that where integrated systems are not available we shouldn't be screening (57). Undertaking service audit

to identify local prevalence of elevated DD may have greater merit enabling business cases to be developed for the provision of psychological care pathways in diabetes.

The treatment and management of Diabetes Distress: a systematic review

Methods

Given the relative novelty of clinical detection and management of DD in clinical practice outside of research studies, we sought to undertake a systematic approach to the identification and appraisal of effective treatment and management strategies. We updated a previous review of effective interventions for reducing DD in type 1 and type 2 populations (28). We searched Medline, Psychinfo and Embase from March 2013 to March 2015, for additional research studies reporting diabetes distress outcomes using the full PAID or DDS. From our previous review (28) 14 type 1 studies, were included. Figure 1 illustrates our combined flow diagram of included studies. The updated search identified 293 citations and two people assessed each. Mixed diabetes population studies were included where the type 1 population data could be reported separately. One further unique experimental study was included. Two papers, published post March 2015, were identified through personal contacts. Due to heterogeneity in both intervention and research design we undertook a narrative synthesis.

Figure 1. Flow diagram of included studies

Managing diabetes distress

Seventeen studies reporting DD related intervention outcomes specifically for adults with T1DM were identified; of these 8 were RCTs, and 9 were pre-post studies. The PAID was used in 15 studies and the DDS in 2 studies. These studies are described in Table 1. Reduction of DD was the sole or co-primary outcome in two studies (56, 69) and a secondary outcome in the remainder. This indicates that the majority of studies are not targeting DD but rather determining whether an intervention targeting another outcome, worsens or improves DD. Reduction of DD was reported in all studies, however not always significantly. Our synthesis has categorised interventions into three groups: Diabetes self-management education (DSME); Self-management with a psychological component and; Devices.

Table 1. Characteristics of intervention studies

Six studies investigated DSME interventions which aimed to reduce HbA1c by providing knowledge about diabetes and the technical skills needed to manage the condition and may include goal-setting and problem-solving. All DSME intervention studies but one (50) (who did not report significance levels) reported significant reductions in DD (35, 70-73) and in HbA1c when reported (35, 71, 72). The DSME Intervention studies were pre-post design and five of the six evaluated the DAFNE programme (Dose Adjustment For Normal Eating) and thus are generally more homogeneous which may account for the consistent positive impact on DD across these DSME interventions. The RCT studies of DAFNE (74) did not report DD as an outcome and so it is not possible to be definitively convinced that DSME, and DAFNE in particular, improved DD compared to controls. A study to evaluate the impact of the DAFNE program on people with elevated DD would be an important next step in the evaluation of both DAFNE and elevated DD.

Nine studies comprised our second category, self-management interventions with a psychological component. In addition to some degree of self-management education these studies have a psychological component focusing on the multidimensional aspects and perceptions of living with diabetes. These interventions aim to develop strategies to cope with the emotional stress of managing the disease and modify unhelpful cognitions. In addition, knowledge provided by the self-management components is utilised by focusing on experiential learning that influence behaviours, psychological adaptation and glycaemic control (56, 69, 75-81). The results of these were less clear regarding significant changes in DD. Four studies showed significant reductions of DD in addition to significant reductions in HbA1c (76, 77, 80, 81). Zoffmann et al (2015) showed significant reductions of both DD and HbA1c in women but not in men (78). In two pilot studies Snoek et al (2001) showed significant reductions in Hba1c and marginally significant reduction in DD ($p=0.06$) and Esbit et al (2014) reported an effect size of 0.34 relating to DD but no effect on Hba1c (69, 79). Likewise, Due-Christensen (2012) reported an effect size of 0.55 relating to reduction in DD ($p \leq 0.001$) but no change in HbA1c was seen (56). Interventions were primarily delivered by diabetes educators. Psychologists or psychiatrists were part of the intervention in 6 studies (56, 69, 75, 76, 79, 81). The psychological intervention components were empowerment and supportive counselling, use of self-determination approaches, and Cognitive Behaviour Therapy (CBT).

Two studies tested the efficacy of devices, Continuous Glucose Monitoring (61) and Sensor Augmented Pump therapy (82). Pump-initiation with 3 individual sessions focusing on blood glucose control reduced DD as compared to Multiple Daily Injection (MDI) treatment (82). DD was not

affected negatively by use of CGM with either real time or retrospective bio-feedback (61).

The most common feature of effective interventions across the 17 studies was the group format which likely taps into natural social support, social learning theory and social comparison theory enabling people to establish a sense of normalcy and acquire positive vicarious learning experiences which successfully aid in breaking isolation and feelings of loneliness in living with type 1 diabetes (83). Groups aimed to share how participants addressed emotional or cognitive problems in relation to performing diabetes specific behaviours and challenges in coping with the demands of diabetes. Problem-solving, goal-setting, focus on motivational barriers and facilitators were also utilised. Homework sheets were used to develop person specific knowledge of illness perception and to enhance reflection on beliefs and attitudes towards diabetes that might need to be changed or reinforced. Studies using a group format and goal setting, problem-solving, reflection, written homework, motivational focus, supportive listening, cognitive restructuring, and addressing emotional challenges seem to offer greater reductions in DD and HbA1c.

The populations under study were predominantly mid-forties with diabetes duration of more than 13 years displaying levels of DD ranging from 20 to 44.4 on PAID with the majority scoring > 30. The review has identified a lack of interventions targeting elevated DD, aiming at emerging adults and also older adults. As it seems DD is present throughout the lifespan it would be important to address this during the early years of adulthood and also in the early stages of diabetes to prevent longstanding DD. In addition, interventions targeting older adults with DD relating to a more severe disease because of complications might be beneficial.

To summarise, the management of DD in type 1 is in its infancy in relation to both research evidence and clinical practice. DSME appears to reduce DD in type 1. Psychologically enhanced self-management interventions reviewed were more heterogeneous than the DSME, predominantly DAFNE, studies that we have reviewed. Nonetheless, these theory based interventions may have the potential to address elevated DD. Group based interventions appear to have merit.

Conclusions

Summary of evidence

This comprehensive review of the topic has identified that elevated Diabetes Distress is experienced by 20-30% of people with type 1 diabetes, that there are well validated scales for assessing DD and whilst many intervention studies have assessed for it, few have targeted elevated DD. There is a

rising imperative to clinically consider the role of elevated DD when providing routine care for type 1 populations. There is growing, albeit currently underdeveloped, evidence of a relationship between DD, self-management behaviours and glycaemic control. There is enough evidence though to warrant the further exploration of the role of elevated DD in influencing HbA1c and self-management behaviours crucial to good diabetes health such as blood glucose monitoring and insulin administration or restriction.

Controversial issues

Cross-sectional evidence developed in type 2 diabetes is contradictory and ambiguous; investigators have found DD to be independently associated with some self-management behaviours and to explain some, albeit not all, of the associations of depressive symptoms with these outcomes (42, 84), others have shown that it is depressive symptoms, not DD, that exhibits an independent association with self-management behaviours (40, 85). Whilst prospective research has found self-management behaviours specifically related to diabetes, and which directly influence HbA1c (i.e. medication adherence), are influenced by DD, whereas only depressive symptoms impacts other more lifestyle oriented behaviours including those that are recommended in diabetes (40). This evidence is not available in type 1.

Recommendations for further research

As the focus of DD research has shifted to Type 1 diabetes only very recently, many important questions remain. Much of the extant research is in younger adults, for example those aged 18-35 years. Most of the research in Type 1 has been done in Scandinavian countries, namely Norway and Denmark potentially limiting the generalisability of the findings. It remains unclear whether diabetes specialist clinicians are able to detect DD clinically within their routine consultations and, more so, what is the impact on detection rates when a clear care pathway for elevated DD exists? Diabetes population screening, using the available validated tools, is not appropriate in the absence of effectiveness and cost effectiveness evidence related to caseness. Research in these areas has not yet commenced.

People with DD and without co-morbid depression may be more responsive to intervention which presents a case for research to detect and manage DD. The prevalence and natural history of DD and DD with co-morbid depression is unknown at the diabetes population level. DSME appears to reduce DD in type 1 and many national diabetes policies recommend the routine provision of DSME. People experiencing elevated DD are likely to need greater support to achieve DSME participation but the

benefits to them may well outweigh the additional resource required to engage them in DSME. Research to evaluate the impact of DSME in patients with elevated DD is warranted. Evidence of one to one or ehealth/mhealth interventions, and research in older age participants, is lacking.

Work delineating the prospective, time-varying, associations between DD and HbA1c and self-management behaviours, whilst accounting for depressive symptoms, is required in Type 1 diabetes. Should these relationships be confirmed, it is critical to then establish the causal linkages between these variables, the pace of the associations, the complex interactive biological, behavioural and affective mechanisms/third variables involved, and the contextual and individual difference variable that determine these associations and their causal pathways (e.g. stage of disease, age, gender, burden of disease, presence of co-morbidities) (86). Once this evidence base has been established, there is a need to then develop and test interventions targeting DD, the mechanisms that underpin the association of DD and HbA1c, and specific sub-groups at risk of high DD and for whom the DD/HbA1c association is particularly strong, in order to maximise outcomes in Type 1 diabetes. Such studies should also elicit the mechanisms, mediators and moderators of any improvement in DD and other endpoints.

A few of these questions have been explored in type 2 diabetes and there is a need to continue to understand the similarities and differences in the causes and consequences of, and treatment options for, DD as they relate to type 1 and type 2 populations.

Compliance with Ethics Guidelines

Conflict of Interest

Jackie Sturt, Kathryn Dennick, and Kate McCarthy declare that they have no conflict of interest.

Mette Due-Christensen reports salary and research funding from Foundation of European Nurses in Diabetes ((FEND) and salary from Steno Diabetes Centre. Dr. Due-Christensen is presently employed at Steno Diabetes Centre A/S. Steno Diabetes Centre is a research hospital and an integrated part of the public Danish National Health Service that is owned by Novo Nordisk A/S. Steno Diabetes Centre receives part of its core funding from unrestricted grants from the Novo Nordisk Foundation and Novo Nordisk A/S. Dr. Due-Christensen owns shares in Novo Nordisk. No potential conflicts of interest relevant to this article exist.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

References

1. Fisher L, Gonzalez JS, Polonsky WH. The confusing tale of depression and distress in patients with diabetes: a call for greater clarity and precision. *Diabetic Medicine*. 2014;31(7):764-72. PubMed PMID: 24606397. Pubmed Central PMCID: 4065190. Epub 2014/03/13. eng.
2. Esbitt SA, Tanenbaum ML, Gonzalez JS. Disentangling clinical depression from diabetes-specific distress: making sense of the mess we've made. 2013. In: *Screening for depression and other psychological problems in diabetes* [Internet]. London: Springer-Verlag. Available from: <http://shibboleth.ovid.com/secure/?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc10&AN=2012-23566-002>
http://sfx.kcl.ac.uk/kings?sid=OVID:psycdb&id=pmid:&id=doi:10.1007%2F978-0-85729-751-8_2&genre=article&atitle=Disentangling+clinical+depression+from+diabetes-specific+distress%3A+Making+sense+of+the+mess+we%27ve+made.&title=&issn=&date=2013&volume=&issue=&spage=27&aualast=Esbitt%2C+Sabrina+A&isbn=978-0-85729-750-1&_char_set=utf8.
3. Friis AM, Johnson MH, Cutfield RG, Consedine NS. Does kindness matter? Self-compassion buffers the negative impact of diabetes-distress on HbA. *Diabetic medicine : a journal of the British Diabetic Association*. 2015 Apr 2. PubMed PMID: 25845983. Epub 2015/04/08. Eng.
4. Sturt J, Dennick K, Hessler D, Hunter B, Oliver J, Purrsell E, et al. High rates of elevated diabetes distress in research populations: a systematic review and meta-analysis. *Diabetes UK Professional Conference*; London, United Kingdom 2015.
5. Lerman-Garber I, Barron-Urbe C, Calzada-Leon R, Mercado-Atri M, Vidal-Tamayo R, Quintana S, et al. Emotional dysfunction associated with diabetes in Mexican adolescents and young adults with type-1 diabetes. *Salud Publica de Mexico*. 2003 2003;45(1):13-8. PubMed PMID: 2003099427.
6. Martyn-Nemeth P, Quinn L, Hacker E, Park H, Kujath AS. Diabetes distress may adversely affect the eating styles of women with type 1 diabetes. *Acta Diabetologica*. 2014 Aug;51(4):683-6. PubMed PMID: WOS:000340507200023. English.
7. Reddy J, Wilhelm K, Campbell L. Putting PAID to diabetes-related distress: the potential utility of the problem areas in diabetes (PAID) scale in patients with diabetes. *Psychosomatics*. 2013 Jan-Feb;54(1):44-51. PubMed PMID: 23295006.
8. Balfe M, Doyle F, Smith D, Sreenan S, Brugha R, Hevey D, et al. What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. *BMC Endocrine Disorders*. 2013 Jul 2013;13(25). PubMed PMID: 2013497111.
9. Tanenbaum ML, Gonzalez JS. The influence of diabetes on a clinician-rated assessment of depression in adults with type 1 diabetes. *Diabetes Educator*. 2012 Sep-Oct;38(5):695-704. PubMed PMID: 22814358.
10. Sturt J MK, Dennick K, Narasimha M, Sankar S & Kumar S. What characterises Diabetes Distress and its resolution? A documentary analysis. *International Diabetes Nursing*. 2015a.
11. Snoek FJ, Bremmer MA, Hermanns N. Constructs of depression and distress in diabetes: time for an appraisal. *Lancet Diabetes Endocrinol*. 2015 Jun;3(6):450-60. PubMed PMID: 25995123. Epub 2015/05/23. Eng.
12. Pouwer F, Skinner TC, Pibernik-Okanovic M, Beekman ATF, Cradock S, Szabo S, et al. Serious diabetes-specific emotional problems and depression in a Croatian-Dutch-English Survey from the European Depression in Diabetes [EDID] Research Consortium. *Diabetes Research & Clinical Practice* 2005 Nov;70(2):166-73. PubMed PMID: 15913827.
13. Lloyd CE, Pambianco G, Orchard TJ. Does diabetes-related distress explain the presence of depressive symptoms and/or poor self-care in individuals with Type 1 diabetes? *Diabetic Medicine*. 2010 Feb;27(2):234-7. PubMed PMID: 20546270. Pubmed Central PMCID: NIHMS293583
PMC3093054.

14. Ehrmann D, Hermanns N, Kulzer B, Bergis N, Maier B, Haak T. Depression in diabetes: The role of diabetes-related distress on incidence and recovery. *Diabetologia*. 2013;Conference:49th Annual Meeting of the European Association for the Study of Diabetes, EASD 2013 Barcelona Spain. Conference Start: 20130923 Conference End: 7. Conference Publication: (var.pagings). 56 (pp S463). PubMed PMID: 71439574.
15. Snoek FJ, Kersch NY, Eldrup E, Harman-Boehm I, Hermanns N, Kokoszka A, et al. Monitoring of Individual Needs in Diabetes (MIND)-2: follow-up data from the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) MIND study. *Diabetes care*. 2012 Nov;35(11):2128-32. PubMed PMID: 22837364. Pubmed Central PMCID: 3476905. Epub 2012/07/28. eng.
16. Ehrmann D, Hermanns N, Haak T, Kulzer B. The influence of diabetes-related distress on depression. *Diabetes*. 2014 2014;Conference:74th Scientific Sessions of the American Diabetes Association San Francisco, CA United States. Conference Start: 20140613 Conference End: 7. Conference Publication: (var.pagings). 63 (pp A201). PubMed PMID: 71559179.
17. Gask L, Macdonald W, Bower P. What is the relationship between diabetes and depression? a qualitative meta-synthesis of patient experience of co-morbidity. *Chronic illness*. 2011 Sep;7(3):239-52. PubMed PMID: 21840916. Epub 2011/08/16. eng.
18. Gonzalez JS, Fisher L, Polonsky WH. Depression in diabetes: have we been missing something important? *Diabetes care*. 2011 Jan;34(1):236-9. PubMed PMID: 21193621. Pubmed Central PMCID: 3005471. Epub 2011/01/05. eng.
19. Polonsky W, Anderson B, Lohrer P, Welch G, Jacobson A, Aponte J, et al. Assessment of diabetes-related distress. *Diabetes care*. 1995;18(6):754-60. PubMed PMID: 1995181556.
20. Polonsky W, Fisher L, Earles J, Dudl RJ, Lees J, Mullan J, et al. Assessing psychosocial distress in diabetes: development of the diabetes distress scale. *Diabetes Care*. 2005 Mar;28(3):626-31. PubMed PMID: 15735199.
21. Joensen LE, Tapager I, Willaing I. Diabetes distress in Type 1 diabetes--a new measurement fit for purpose. *Diabetic medicine : a journal of the British Diabetic Association*. 2013 Sep;30(9):1132-9. PubMed PMID: 23701311. Epub 2013/05/25. eng.
22. Welch G, Weinger K, Anderson B, Polonsky WH. Responsiveness of the Problem Areas In Diabetes (PAID) questionnaire. *Diabet Med*. 2003 Jan;20(1):69-72. PubMed PMID: 12519323. Epub 2003/01/10. eng.
23. Markowitz JT, Volkening LK, Butler DA, Antisdel-Lomaglio J, Anderson BJ, Laffel LM. Re-examining a measure of diabetes-related burden in parents of young people with Type 1 diabetes: the Problem Areas in Diabetes Survey - Parent Revised version (PAID-PR). *Diabet Med*. 2012 Apr;29(4):526-30. PubMed PMID: 21883443. Pubmed Central PMCID: PMC3510480. Epub 2011/09/03. eng.
24. Weissberg-Benchell J, Antisdel-Lomaglio J. Diabetes-specific emotional distress among adolescents: feasibility, reliability, and validity of the problem areas in diabetes-teen version. *Pediatr Diabetes*. 2011 Jun;12(4 Pt 1):341-4. PubMed PMID: 21443583. Epub 2011/03/30. eng.
25. Snoek FJ, Pouwer F, Welch GW, Polonsky WH. Diabetes-related emotional distress in Dutch and U.S. diabetic patients: cross-cultural validity of the problem areas in diabetes scale. *Diabetes Care*. 2000 Sep;23(9):1305-9. PubMed PMID: 10977023. Epub 2000/09/08. eng.
26. Amsberg S, Wredling R, Lins PE, Adamson U, Johansson UB. The psychometric properties of the Swedish version of the Problem Areas in Diabetes Scale (Swe-PAID-20): scale development. *Int J Nurs Stud*. 2008 Sep;45(9):1319-28. PubMed PMID: 17983618. Epub 2007/11/07. eng.
27. Fisher L, Polonsky W, Hessler D, Stryker L, Masharani U, Blumer I, et al. A new validated measure of diabetes distress for adults with Type 1 diabetes. 74th Scientific Sessions of the American Diabetes Association; San Francisco, CA United States 2014.
28. Sturt J, Dennick K, Hessler D, Hunter B, Oliver J, Fisher L. Effective interventions for reducing Diabetes Distress: systematic review and meta-analysis *International Diabetes Nursing*. 2015b.

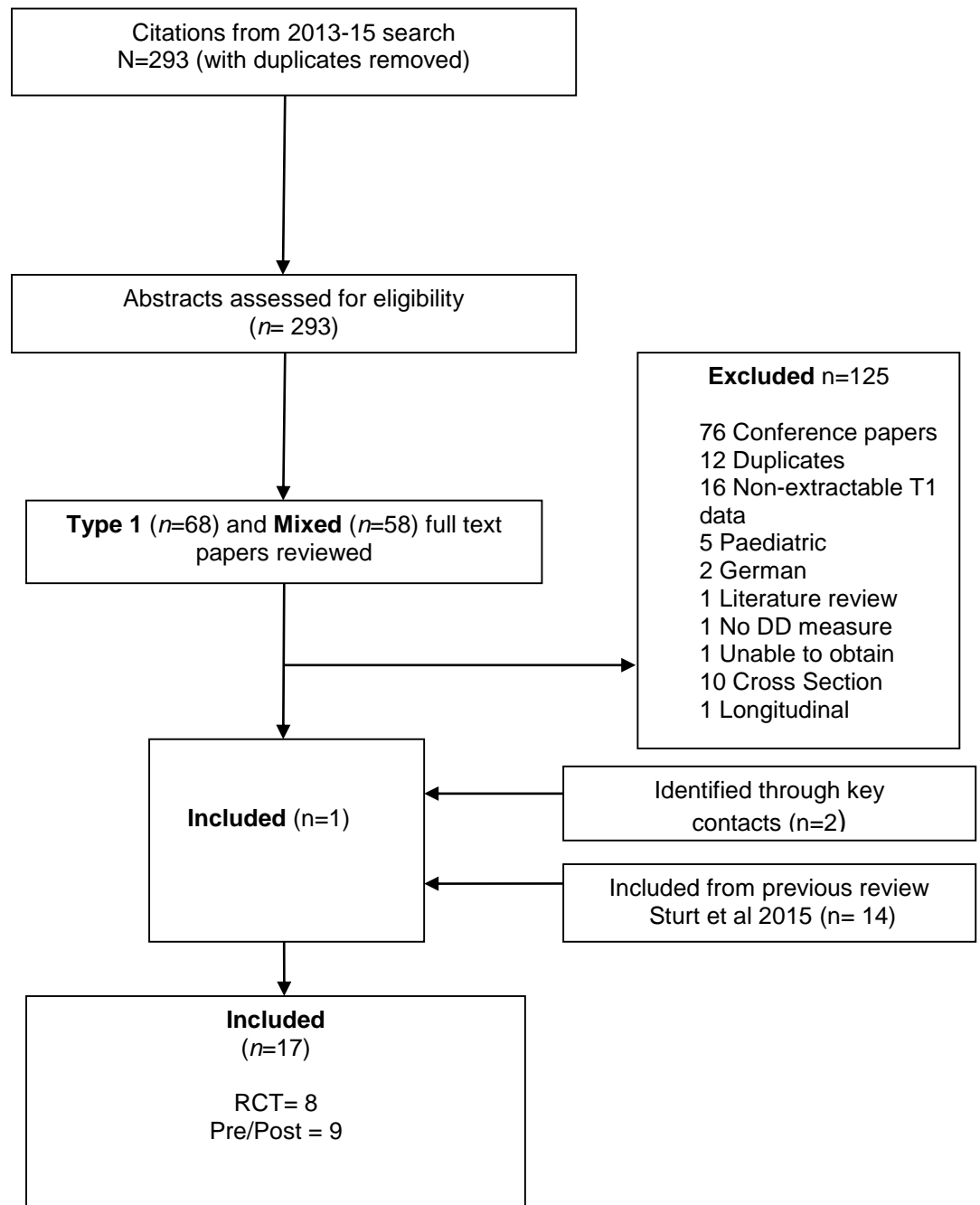
29. Jones A, Olsen MZ, Perrild HJ, Willaing I. The psychological impact of living with diabetes: Descriptive findings from the DAWN2 study in Denmark. Primary care diabetes. 2015 Apr 15. PubMed PMID: 25890864. Epub 2015/04/22. Eng.
30. Fisher L, Glasgow RE, Mullan JT, Skaff MM, Polonsky WH. Development of a brief diabetes distress screening instrument. Annals of family medicine. 2008 May-Jun;6(3):246-52. PubMed PMID: 18474888. Pubmed Central PMCID: 2384991. Epub 2008/05/14. eng.
31. McGuire BE, Morrison TG, Hermanns N, Skovlund S, Eldrup E, Gagliardino J, et al. Short-form measures of diabetes-related emotional distress: the Problem Areas in Diabetes Scale (PAID)-5 and PAID-1. Diabetologia. 2010 Jan;53(1):66-9. PubMed PMID: 19841892.
32. Law GU, Walsh J, Queralto V, Nouwen A. Adolescent and parent diabetes distress in type 1 diabetes: The role of self-efficacy, perceived consequences, family responsibility and adolescent-parent discrepancies. Journal of Psychosomatic Research. 2013 2013;74(4):334-9.
33. Strandberg RB, Graue M, Wentzel-Larsen T, Peyrot M, Thordarson HB, Rokne B. Longitudinal relationship between diabetes-specific emotional distress and follow-up HbA1c concentration in adults with Type 1 diabetes. Diabet Med. 2015.
34. Peyrot M MJJ, Kruger DF. A biopsychosocial model of glycaemic control in diabetes: stress, coping and regimen adherence. . Journal of Health and Social Behaviour. 1999;40(2):141-58.
35. Weinger K, Jacobson AM. Psychosocial and quality of life correlates of glycemic control during intensive treatment of type 1 diabetes. Patient Education and Counseling. 2001 Feb;42(2):123-31. PubMed PMID: 11118778.
36. Zagarins SE, Allen NA, Garb JL, Welch G. Improvement in glycemic control following a diabetes education intervention is associated with change in diabetes distress but not change in depressive symptoms. Journal of Behavioral Medicine. 2012 Jun;35(3):299-304. PubMed PMID: 21691844. Epub 2011/06/22. eng.
37. Ali Z, Patel NH. Glycaemic control, emotional attitudes and quality of life in patients living with Type 1 diabetes. Diabetic Medicine. 2013 2013;Conference:Diabetes UK Professional Conference 2013 Manchester United Kingdom. Conference Start: 20130313 Conference End: 5. Conference Publication: (var.pagings). 30 (pp 104-105). PubMed PMID: 71019054.
38. Sheils E, Knott J, Cavan D, Shaban C. Fear of hypoglycaemia: Is there an association with glycaemic control, hypoglycaemic symptoms and diabetes emotional distress in people with Type 1 diabetes? Diabetic Medicine. 2012 2012;Conference:Diabetes UK Professional Conference 2012 Glasgow United Kingdom. Conference Start: 20120307 Conference End: 9. Conference Publication: (var.pagings). 29 (pp 157). PubMed PMID: 70696196.
39. Strandberg RB, Graue M, Wentzel-Larsen T, Peyrot M, Rokne B. Relationships of diabetes-specific emotional distress, depression, anxiety, and overall well-being with HbA1c in adult persons with type 1 diabetes. Journal of Psychosomatic Research. 2014 Sep;77(3):174-9. PubMed PMID: 25149027.
40. Aikens JE. Prospective associations between emotional distress and poor outcomes in type 2 diabetes. Diabetes Care. 2012 Dec;35(12):2472-8. PubMed PMID: 23033244. Pubmed Central PMCID: PMC3507577.
41. Fisher L, Mullan JT, Arean P, Glasgow RE, Hessler D, Masharani U. Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. Diabetes care. 2010;33(1):23-8. PubMed PMID: 19837786. Pubmed Central PMCID: PMC2797978.
42. Fisher L, Glasgow RE, Strycker LA. The relationship between diabetes distress and clinical depression with glycemic control among patients with type 2 diabetes. Diabetes care. 2010 May;33(5):1034-6. PubMed PMID: 20150291. Pubmed Central PMCID: PMC2858170.
43. Polonsky WH AB, Lohrer PA, Jaconson AM, Cole CF. Insulin omission in women with IDDM. Diabetes Care. 1994;10:1178-85.
44. Goebel-Fabbri AE AB, Fikkan J, Franko DL, Pearson K, Weinger K. Improvement and emergence of insulin restriction in women with type 1 diabetes. Diabetes Care. 2011;34(3):545-50.

45. van Bastelaar KM, Pouwer F, Geelhoed-Duijvestijn PH, Tack CJ, Bazelmans E, Beekman AT, et al. Diabetes-specific emotional distress mediates the association between depressive symptoms and glycaemic control in Type 1 and Type 2 diabetes. *Diabetic Medicine*. 2010 Jul;27(7):798-803. PubMed PMID: 20636961. Epub 2010/07/20. eng.
46. Pibernik-Okanovic M, Grgurevic M, Begic D, Szabo S, Metelko Z. Interaction of depressive symptoms and diabetes-related distress with glycaemic control in Type 2 diabetic patients. *Diabetic Medicine*. 2008 Oct;25(10):1252-4. PubMed PMID: 19046209.
47. Schmitt A, Reimer A, Kulzer B, Haak T, Gahr A, Hermanns N. Negative association between depression and diabetes control only when accompanied by diabetes-specific distress. *Journal of Behavioral Medicine*. 2014 Jun;38(3):556-64. PubMed PMID: 25326733. Epub 2014/10/20. eng.
48. Graue M, Haugstvedt A, Wentzel-Larsen T, Iversen MM, Karlsen B, Rokne B. Diabetes-related emotional distress in adults: Reliability and validity of the Norwegian versions of the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS). *International Journal of Nursing Studies*. 2012 2012;49(2):174-82. PubMed PMID: 21924422.
49. Zoffmann V, Vistisen D, Due-Christensen M. A cross-sectional study of glycaemic control, complications and psychosocial functioning among 18- to 35-year-old adults with type 1 diabetes. *Diabetic Medicine*. 2014 Apr;31(4):493-9. PubMed PMID: 24236961.
50. Byrne M, Newell J, Coffey N, MC OH, Cooke D, Dinneen SF. Predictors of quality of life gains among people with type 1 diabetes participating in the Dose Adjustment for Normal Eating (DAFNE) structured education programme. *Diabetes Res Clin Pract*. 2012 Nov;98(2):243-8. PubMed PMID: 23018180. Epub 2012/09/29. eng.
51. Ting RZ, Nan, H., Mandy, W. M., Kong, A. P., Ma, R. C., Wong, R. Y., ... & Chan, J. C. Diabetes-related distress and physical and psychological health in Chinese type 2 diabetic patients *Diabetes Care*. 2011;34(5):1094-6.
52. West C, McDowell J. The distress experienced by people with type 2 diabetes. *British Journal of Community Nursing*. 2002 Dec;7(12):606-13. PubMed PMID: 12514489.
53. Fisher L, Hessler DM, Polonsky WH, Mullan J. When is diabetes distress clinically meaningful?: establishing cut points for the Diabetes Distress Scale. *Diabetes Care*. 2012 Feb;35(2):259-64. PubMed PMID: 22228744. Pubmed Central PMCID: PMC3263871.
54. Rosenbek Minet LK, Wagner L, Lonvig EM, Hjelmberg J, Henriksen JE. The effect of motivational interviewing on glycaemic control and perceived competence of diabetes self-management in patients with type 1 and type 2 diabetes mellitus after attending a group education programme: a randomised controlled trial. *Diabetologia*. 2011 Jul;54(7):1620-9. PubMed PMID: 21455729. Epub 2011/04/02. eng.
55. Psychological effects of continuous glucose monitoring in type 1-diabetes. *Verhaltenstherapie & Verhaltensmedizin*. 2009;30(4):458-69. Psychologische effekte der kontinuierlichen glukosemessung bei typ-1-diabetes.
56. Due-Christensen M, Zoffmann V, Hommel E, Lau M. Can sharing experiences in groups reduce the burden of living with diabetes, regardless of glycaemic control? *Diabetic Medicine*. 2012 Feb;29(2):251-6. PubMed PMID: 22061095.
57. Fleer J, Tovote KA, Keers JC, Links TP, Sanderman R, Coyne JC, et al. Screening for depression and diabetes-related distress in a diabetes outpatient clinic. *Diabet Med*. 2013 Jan;30(1):88-94. PubMed PMID: 22924587. Epub 2012/08/29. eng.
58. Hermanns N, Kulzer B, Krichbaum M, Kubiak T, Haak T. How to screen for depression and emotional problems in patients with diabetes: comparison of screening characteristics of depression questionnaires, measurement of diabetes-specific emotional problems and standard clinical assessment. *Diabetologia*. 2006 Mar;49(3):469-77. PubMed PMID: 16432706.
59. Duda-Sobczak A, Zozulinska-Ziolkiewicz D, Pisarczyk-Wiza D, Wierusz-Wysocka B. The assessment of factors related to depressive symptoms in adult patients with type 1 diabetes. *Diabetologia*. 2014 2014;Conference:50th Annual Meeting of the European Association for the Study

- of Diabetes, EASD 2014 Vienna Austria. Conference Start: 20140915 Conference End: 9. Conference Publication: (var.pagings). 57 (1 SUPPL. 1) (pp S420-S421). PubMed PMID: 71595672.
60. Kibbey KJ, Speight J, Wong JLA, Smith LA, Teede HJ. Diabetes care provision: barriers, enablers and service needs of young adults with Type 1 diabetes from a region of social disadvantage. *Diabetic Medicine*. 2013 Jul;30(7):878-84. PubMed PMID: 23659590.
 61. Hermanns N, Kulzer B, Gulde C, Eberle H, Pradler E, Patzelt-Bath A, et al. Short-term effects on patient satisfaction of continuous glucose monitoring with the GlucoDay with real-time and retrospective access to glucose values: a crossover study. *Diabetes Technol Ther*. 2009 May;11(5):275-81. PubMed PMID: 19425875. Epub 2009/05/12. eng.
 62. Nicolucci A, Kovacs Burns K, Holt R, Comaschi M, Hermanns N, Ishii H, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2™): Cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabetic Medicine*. 2013;30(7):767-77.
 63. Luyckx K, Rassart J, Weets I. Illness self-concept in Type 1 diabetes: A cross-sectional view on clinical, demographic, and psychosocial correlates. *Psychology, Health & Medicine*. 2015 2015;20(1):77-86.
 64. Brierley S, Johnson B, Young V, Eiser C, Heller S. The importance of measuring diabetes distress in young people with Type 1 diabetes. *Diabetic Medicine*. 2012 2012;Conference:Diabetes UK Professional Conference 2012 Glasgow United Kingdom. Conference Start: 20120307 Conference End: 9. Conference Publication: (var.pagings). 29 (pp 159). PubMed PMID: 70696202.
 65. Joensen LE, Almdal TP, Willaing I. Type 1 diabetes and living without a partner: psychological and social aspects, self-management behaviour, and glycaemic control. *Diabetes Research & Clinical Practice*. 2013 Sep;101(3):278-85. PubMed PMID: 23891305.
 66. Association AD. Standards of Medical Care in Diabetes. *Diabetes Care*. 2015;38(Supplement 1):S1-S94.
 67. Hajos T, Pouwer F, Skovlund S, Den Oudsten B, Geelhoed-Duijvestijn P, Tack C, et al. Psychometric and screening properties of the WHO-5 well-being index in adult outpatients with Type 1 or Type 2 diabetes mellitus. *Diabetic Medicine*. 2013;30(2):e63-e9.
 68. Pouwer F, Beekman AT, Lubach C, Snoek FJ. Nurses' recognition and registration of depression, anxiety and diabetes-specific emotional problems in outpatients with diabetes mellitus. *Patient Educ Couns*. 2006 Feb;60(2):235-40. PubMed PMID: 16442465. Epub 2006/01/31. eng.
 69. Snoek FJ, Van Der Ven, N. C. W., Lubach, C. H. C., Chatrou, M., Ader, H. J., Heine, R. J., & Jacobson, A. M. Effects of cognitive behavioural group training (CBGT) in adult patients with poorly controlled insulin-dependent (type 1) diabetes: A pilot study. *Patient Education and Counseling*. 2001;45(2):143-8. PubMed PMID: 2001381387.
 70. Engel L, Cummins R. Impact of dose adjustment for normal eating in Australia (OzDAFNE) on subjective wellbeing, coping resources and negative affects in adults with type 1 diabetes: a prospective comparison study. *Diabetes Research & Clinical Practice*. 2011 Mar;91(3):271-9. PubMed PMID: 21146889.
 71. Hopkins D, Lawrence I, Mansell P, Thompson G, Amiel S, Campbell M, et al. Improved Biomedical and Psychological Outcomes 1 Year After Structured Education in Flexible Insulin Therapy for People With Type 1 Diabetes: The U.K. DAFNE experience. *Diabetes Care*. 2012 August 1, 2012;35(8):1638-42.
 72. Keen AJA, Duncan E, McKillop-Smith A, Evans ND, Gold AE. Dose Adjustment for Normal Eating (DAFNE) in routine clinical practice: who benefits? *Diabetic Medicine*. 2011 May;29(5):670-6. PubMed PMID: 21988559.
 73. McIntyre HD, Knight BA, Harvey DM, Noud MN, Hagger VL, Gilshenan KS. Dose adjustment for normal eating (DAFNE) - an audit of outcomes in Australia. *Medical Journal of Australia*. 2010 Jun 7;192(11):637-40. PubMed PMID: 20528716.
 74. Group. DS. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. *British Medical Journal*. 2002;325(7367):746.

75. Snoek FJ, van der Ven NCW, Twisk JWR, Hogenelst MHE, Tromp-Wever AME, van der Ploeg HM, et al. Cognitive behavioural therapy (CBT) compared with blood glucose awareness training (BGAT) in poorly controlled Type 1 diabetic patients: long-term effects on HbA moderated by depression. A randomized controlled trial. *Diabetic Medicine*. 2008 Nov;25(11):1337-42. PubMed PMID: 19046225.
76. Amsberg S, Anderbro T, Wredling R, Lisspers J, Lins PE, Adamson U, et al. A cognitive behavior therapy-based intervention among poorly controlled adult type 1 diabetes patients--a randomized controlled trial. *Patient Educ Couns*. 2009 Oct;77(1):72-80. PubMed PMID: 19297117. Epub 2009/03/20. eng.
77. Zoffmann V, Lauritzen T. Guided self-determination improves life skills with type 1 diabetes and A1C in randomized controlled trial. *Patient Educ Couns*. 2006 Dec;64(1-3):78-86. PubMed PMID: 16720089. Epub 2006/05/25. eng.
78. Zoffmann V, Vistisen D, Due-Christensen M. Flexible guided self-determination intervention for younger adults with poorly controlled Type 1 diabetes, decreased HbA and psychosocial distress in women but not in men: a real-life RCT. *Diabetic Medicine*. 2015 Jan 19. PubMed PMID: 25601214. Epub 2015/01/21. Eng.
79. Esbitt SA, Batchelder AW, Tanenbaum ML, Shreck E, Gonzalez JS. "Knowing That You're Not the Only One": Perspectives on Group-Based Cognitive-Behavioral Therapy for Adherence and Depression (CBT-AD) in Adults With Type 1 Diabetes. *Cognitive and Behavioral Practice*. 2014 (0).
80. Hermanns N, Kulzer B, Ehrmann D, Bergis-Jurgan N, Haak T. The effect of a diabetes education programme (PRIMAS) for people with type 1 diabetes: results of a randomized trial. *Diabetes Res Clin Pract*. 2013 Dec;102(3):149-57. PubMed PMID: 24210673. Epub 2013/11/12. eng.
81. Hermanns N, Schmitt A, Gahr A, Herder C, Nowotny B, Roden M, et al. The effect of a Diabetes-Specific Cognitive Behavioral Treatment Program (DIAMOS) for patients with diabetes and subclinical depression: results of a randomized controlled trial. *Diabetes Care*. 2015 Apr;38(4):551-60. PubMed PMID: 25605812. Epub 2015/01/22. eng.
82. Hermanides J, Norgaard K, Bruttomesso D, Mathieu C, Frid A, Dayan CM, et al. Sensor-augmented pump therapy lowers HbA(1c) in suboptimally controlled Type 1 diabetes; a randomized controlled trial. *Diabet Med*. 2011 Oct;28(10):1158-67. PubMed PMID: 21294770. Epub 2011/02/08. eng.
83. Solomon P. Peer Support/Peer Provided Services Underlying Processes, Benefits, and Critical Ingredients. *Psychiatric Rehabilitation Journal*. 2004;27(4):392-401.
84. Fisher L, Skaff MM, Mullan JT, Arean P, Mohr D, Masharani U, et al. Clinical depression versus distress among patients with type 2 diabetes: not just a question of semantics. *Diabetes Care*. 2007;30(3):542-8. PubMed PMID: 17327318.
85. Gonzalez JS, Delahanty LM, Safren SA, Meigs JB, Grant RW. Differentiating symptoms of depression from diabetes-specific distress: relationships with self-care in type 2 diabetes. *Diabetologia*. 2008 Oct;51(10):1822-5. PubMed PMID: 18690422. Pubmed Central PMCID: 2678064. Epub 2008/08/12. eng.
86. Hessler D, Fisher L, Glasgow RE, Strycker LA, Dickinson LM, Arean PA, et al. Reductions in regimen distress are associated with improved management and glycemic control over time. *Diabetes Care*. 2014 Mar;37(3):617-24. PubMed PMID: 24170750. Pubmed Central PMCID: 3931383. Epub 2013/10/31. eng.

Fig 1: Flow diagram of included studies



Reference, Year, Country, Methodology	Recruited, I/C group size, Length of follow-up, Intention-to-treat Y/N, Primary outcome, Diabetes Distress Measure	Mean Age, Male%, T1%, Diabetes duration years	Baseline Diabetes Distress (I/C)	Baseline HbA1c (I/C)	Intervention description Speciality of therapist Control Group	Outcomes
Randomised Control Trials						
Zoffman, 2006, Denmark, RCT (78)	61, I:61 / C:25, 12m, N, NR, PAID	36yrs, I:46 C:50, T1: 100%, NR	I:32 (3.4) C:40.9 (4.0)	I:9.01 (0.2); C:9.05 (0.2)	Empowerment theory based, self-determination theory (SDT), self-directed written materials encouraging reflection, goal and problem solving oriented; supportive listening, motivational focus. Group face-to-face, by diabetes educator, 7x 2hour sessions over 8 weeks. <i>Waiting list control</i>	PAID I: 25.6 (2.7); C: 36.7 (4.5), (p<0.05) The intervention group did better than controls re: increased autonomy support perceived from HCPs, higher frequency of self-monitored blood glucoses, increased perceived competence in managing diabetes, reduced diabetes distress (total score and generally consistent for sub-scales esp. treatment-related social support distress). HbA1c reduced (0.41%) between I and C groups showing a modest but long-term effect of the intervention.
Snoek, 2008, Dutch, RCT (76)	86, I:45 / C:41, 12m, Y, HbA1c, PAID	I:38yrs C:37yrs, I:49 C:34, T1: 100%, I:17.8 (10.1) C:18.8 (10.9)	I:44.4 (22.4) C:49.0 (17.2)	I:8.8 (1.3); C:9.1 (1.1)	Theory based CBT, addressing psychological barriers to diabetes self-management, reframing of negative beliefs, written homework assignments. 6x group sessions delivered weekly by a psychologist. <i>Six blood glucose awareness training sessions delivered weekly.</i>	PAID: I: 43.4 reduced to 38.3; C: 49.0 reduced to 45.4 (Intervention x time, 6 months $p=0.99$; 12 months $p=0.68$) Significant effect for HbA1c reduction in subgroup of depressed patients with CBT but not the BGAT group. HbA1c no significant changes
Hermanns, 2009, German, RCT crossover (62)	50, 50 crossover, 12wks, N, CGM satisfaction, PAID	42yrs, 53%, T1:100%, 14.75 (11.9)	30.7 (18.8)	I:8.1 (1.5)	Glucose Monitoring Device education, single in-patient stay averaging 42 hours, individual face-to-face session, delivered by a diabetes specialist, Continuous Glucose Monitoring with real time access to results. <i>Same group -with retrospective analysis of glucose data. Order of condition randomized.</i>	PAID baseline: 30.7 (18.8), RA: 28.5 (19.2), RTA 29.2 (21.2) (NS) No significant reduction in distress from baseline in either group, nor between group differences. Continuous Glucose Monitoring was less desirable compared to baseline and the real time or retrospective analysis of data made no difference to this outcome.
Amsberg, 2009, Sweden, RCT (77)	74, I:36 / C:38, 48wks, Y, HbA1c, PAID	41yrs, 49, T1:100%, 21.6 (10.8)	I:31.1 (20.4) C:33.4 (17.3)	≥7.5	Theory based CBT, basic programme of 8x 2hr weekly group sessions, plus 2x maintenance group sessions, 2x individual sessions and 5 phone calls Log book for self-care activities and emotions, homework to enhance reflection upon self-care behaviours, supportive counselling delivered by a diabetes specialist nurse and psychologist. <i>Usual care</i>	PAID I: 22.92; C 29.8 (p=0.004) Significant differences in DD between groups were observed at 24-weeks and maintained throughout the study to week 48. Change in HbA1c was significant between groups at 48 weeks I: 7.72; C: 8.21 (p=0.012)
Hermanides, 2011, European, RCT (83)	83, I:22 / C:21, 26wks, Y, HbA1c, PAID	I:39yrs C:37yrs, I:50 C:54, T1:100%, I: 16.9 (10.7) C: 21.0 (9.4)	I:32.4 (18.8) C:26.5 (18.4)	I:8.45 (0.95) C:8.59 (0.82)	Sensor augmented insulin pump treatment, 26 weeks. 1 st 13 weeks no specific instructions given; 2 nd 13 weeks advised to carbohydrate count. <i>Control group on multiple daily injections received standard care. 1st 13 weeks no specific instructions given; 2nd 13 weeks advised to carbohydrate count.</i>	PAID I: 21.0 (19.3) (p=0.03) in favour of Sensor-Augmented Insulin Pump Group. Sensor augmented insulin pump therapy was associated with an improvement in diabetes related distress. HbA1c I: 7.23. (0.65), C: 8.46 (1.04) (p<0.001)

Reference, Year, Country, Methodology	Recruited, I/C group size, Length of follow-up, Intention-to-treat Y/N, Primary outcome, Diabetes Distress Measure	Mean Age, Male%, T1%, Diabetes duration	Baseline Diabetes Distress (I/C)	Baseline HbA1c % (I/C)	Intervention regime and model Speciality of therapist Control Group	Outcomes
Hermanns, 2013, German, RCT (81)	160, I:81 / C:79, 6m, Y, HbA1c, DDS	I:45yrs, C:46yrs, I:51 C:62, T1:100%, I:19.3 (13.4) C:19.6 (12.8)	I:1.3, C:1.2	I:8.3 (1.1); C:8.1 (1.0)	Empowerment/self-management theory based, (PRIMAS), written materials, homework, problem solving, goal setting, addressing emotional problems, 12x 90min group sessions twice weekly over 6 weeks., Family members or other close relations were invited to attend one session on social support. Delivered by diabetes educators. <i>Control: usual DSME programme: written materials, health professional delivered, 12x 90min group sessions.</i>	DDS: I: -0.3 (0.7), C: -0.1 (0.4) (p=0.032) The intervention was superior in reducing diabetes distress, HbA1c and increasing empowerment, self-efficacy and satisfaction with insulin therapy. Both groups improved awareness of hypoglycaemia, diabetes knowledge, self-care behaviour and reduced severe hypoglycaemia incidents with no significant between group differences. HbA1c in I compared to C (-0.4 \pm 1.0% vs. 0.0 \pm 0.6%) (p = 0.012)
Hermanns, 2015, German, RCT (82)	214, I:106 / C:108, 12m, Y, Depressive symptoms, PAID	43yrs, 43, T1: I: 59%, C:72%, 14.2 (10.5)	40.3 (3.4)	8.9 (1.8)	Empowerment/self-management theory based CBT, Diabetes motivation strengthening (DIAMOS) for patients with subclinical depression, 5x 90min group sessions plus telephone support. Coping with diabetes related challenges, goal setting and problem-solving, motivational strategies, self-directed written materials. Delivered by diabetes psychologist. <i>Control group 5x 90min group education intervention delivered by a healthcare professional.</i>	PAID: I: -13.0 (18.9) (p=0.001); C:-4.2 (16.9) (p=0.022) Type 1 specific: more T1 in control group; analysis stratified by diabetes type no significant interaction effects observed except diabetes acceptance (less impact on diabetes acceptance in T1 than T2). DIAMOS efficacious in treating sub-threshold depression and elevated Diabetes Distress more effectively than education alone. Additionally it prevents deterioration from sub to major depression. HbA1c: I:-0.5 (2.0) p=0.018; C: -0.7 (1.7) p=0.001
Zoffman, 2015, Denmark, RCT (79)	200, I:134 / C:66, 18m, Y, HbA1c, PAID	26yrs, 50, T1:100%, 13.7 (6.8),	I:36.4 (21.0), C:35.2 (22.7)	I:9.5 (1.3); C:9.7 (1.5)	Empowerment theory based SDT, self-directed written materials encouraging reflection, goal and problem solving oriented, supportive listening, motivational focus. 7x either 1hr individual sessions or 2.5hr group sessions, over max 12 months. Delivered by diabetes nurse specialists. <i>Control group received usual care (3-4monthly appointment with diabetes specialist).</i>	PAID: Difference between I & C (p<0.001); I: (Men -2.6; Women -15.3) (p= 0.0024) The flexible self-guided determination intervention benefitted younger adult women by significantly improving glycaemic control and decreasing diabetes related distress. No effect was seen among men. HbA1c: I: -0.4%, C: -0.1% (p=0.073)
Pre/Post Intervention Studies						
Weinger, 2001, American, Pre/Post (36)	55, NA, 8wks, N, Emotion/Attitude barriers, PAID	NR, 44, T1:100%, NR	PAID 40.0 (3.4)	9.0	Medical/education programme, 8 weeks with monthly diabetes clinic MDT, weekly phone contact from diabetes nurse to optimise glycaemic control in addition 8 weeks educational programme either BGAT or cholesterol education (no information on group or individual provided).	PAID reduced from 40 to 31 (p<0.01) Newly learned self-management needs assistance to be incorporated into lifestyle. Intervention needs to help identify potential barriers and the necessary steps to achieve self-management goals. PAID particularly useful as a screening tool for patients attempting to improve glycaemic control.HbA1c9.0% to 7.8% (p=0.0001)
Snoek, 2001, Dutch, Pre/Post (70)	24, NA, 6m, N, HbA1c, PAID	35yrs, 38, T1:100%, NR	39.9 (16.0)	9.3 (1.2)	Theory based CBT, group session, to improve coping with diabetes, cognitive restructuring, stress management, behavioural strategies, and homework. 4x1.5hrs sessions weekly, delivered by a diabetes nurse specialist and diabetes psychologist.	PAID reduced 39.9 (16.0) to 31.2 (17.4) (p=0.06) CBGT is feasible in a poorly controlled group; Perceived barriers were decreased significantly; general wellbeing was maintained. HbA1c reduced 9.3%(1.2) to 8.5% (0.91) (p=0.04);
McIntyre, 2010, Australia, Pre/Post (74)	145, NA, 12m, N, HbA1c,	43yrs, 66, T1:100%, 16.7 (11.5)	25.0 (15-45)	8.2 (1.2)	DAFNE programme, theory based, 5 consecutive whole days delivered in groups, to increase diabetes knowledge and self-management skills relating to insulin dose adjustment according to food intake aiming	PAID 25 (15-45) reduced to 16.25 (10-30) (p<0.0001) Improved glycaemic control; reduced severe hypoglycaemia incidents, improved QOL. HbA1c reduced 8.2% to 7.8%

PAID

at patient autonomy, delivered by diabetes specialists MDT.

Reference, Year, Country, Methodology	Recruited, I/C group size, Length of follow-up, Intention-to-treat Y/N, Primary outcome, Diabetes Distress Measure	Mean Age, Male%, T1%, Diabetes duration	Baseline Diabetes Distress (I/C)	Baseline HbA1c % (I/C)	Intervention regime and model Speciality of therapist Control Group	Outcomes
Engle, 2011, Australia, Pre/Post (71)	144, NA, 12m, N, Wellbeing & coping, PAID	45yrs, 35, T1:100%, 17.7 (12.42)	1:31.94 (18.27) MDI 28.12 (20.94); CSII 28.92 (17.11)	NR	DAFNE programme (See McIntyre 2010). <i>Usual care comparison to two groups, multiple daily injections (MDI) and continuous subcutaneous insulin infusion (CSII).</i>	PAID: 1 -10.37 (14.67) (p<0.001); MDI -2.14 (11.38); CSII -3.98 (9.77). OzDAFNE provides a powerful mastery experience, positively influences subjective wellbeing and diabetes related distress.
Keen, 2011, UK, Pre/Post (73)	124, NA, 12m, N, HbA1c, PAID	43yrs, 56, T1:100%, 17.8 (11.0)	20 (12.5-33.8)	8.6%	DAFNE programme (See McIntyre 2010)	PAID: 25 (15-45) reduced to 16.25 (10-30), (p<0.0001) DAFNE reduced diabetes related distress, improved glycaemic control, reduced severe hypoglycaemia, and improved QOL. HbA1c: only the group with \geq 9.6% had significantly lower at 12m (p=0.004)
Byrne, 2012, UK, Pre/Post (51)	437, NA, 18m, N, Predictors of QOL outcomes, PAID	41yrs, 46, T1:100%, 15.9 (10.8)	PAID \geq 33: 166/423 PAID < 32: 257/423	8.3 (1.4)	DAFNE programme (See McIntyre 2010)	PAID: 21.5 (17.92) participants with higher HbA1c and anxiety scores at baseline exhibited the greatest reduction in PAID score. No between group differences on any measures.
Due-Christensen, 2012, Denmark, Pre/Post (57)	54, NA, 12m, Y, Diabetes related distress, PAID	44yrs, 20, T1:100%, 21 (11.7)	37.36 (16.16) \geq 40: 29	8.2 (1.3)	Empowerment theory based, 8 x 2hr 15min group sessions over 3-4 months, peer directed themes e.g. fear of complications, role of the social network, acceptance of diabetes. Motivational strategies, homework sheets to enhance reflection, goal setting, and problem-solving. Delivered by MDT.	PAID: 37.36 (16.16) reduced to 27.92 (17.88), (p\leq0.001; Cohen's D 0.55) Participation in group support lead to reduced diabetes related distress in participants with good and poor glycaemic control. Glycaemic control did not improve at any time point.
Hopkins, 2012, UK, Pre/Post (72)	639, NA, 12m, N, Impact in routine practice, PAID	42yrs, NR, T1:100%, 18.0 (12.1)	25.2 (17.4)	8.51 (1.41)	DAFNE programme (See McIntyre 2010)	PAID: 25.2 (17.4) reduced to 16.7 (14.1), (p<0.001) DAFNE reduces diabetes related distress, improves well-being, reduces hypoglycaemic rates and restores hypoglycaemia awareness. HbA1c fell by 0.27% (p<0.001)
Esbitt, 2014, American, Pre/Post (80)	11, NA, 3m, N, Feasibility of group CBT, DDS	40yrs, 50, T1:100%, 22.38yrs (11.69)	3.19 (0.97)	8.56 (1.04)	Theory based CBT, group-based intervention for depression and adherence, 10x 60-90min sessions over 10 weeks: self-management, depression and diabetes related distress in an integrative manner including: problem solving, goal setting, motivational consultation,	DDS: Pre 3.19 (0.97), Post 2.82 (0.98) (Cohen's d=0.34) Participation in a group CBT was acceptable, associated with reductions in diabetes distress and depressive symptoms. HbA1c mean pre score 8.56% post score 8.73% (Cohen's d= -0.08)

education, written materials, self-management
education. Delivered by diabetes psychologist.

C= Control Group; CBT= Cognitive behavioural therapy; CGM = Continuous Glucose Monitoring; DAFNE=Dose Adjusted for normal eating; DDS= Diabetes Distress Scale; DSME= Diabetes Self-Management Education; I= Intervention Group; M= Months; MDT = Multidisciplinary team; NR= Not reported; NA= Not applicable; PAID= Problem Areas in Diabetes Scale; QOL= Quality of Life; T1= Type 1 Diabetes Mellitus; T2 Type 2 Diabetes Mellitus; wks= weeks; yrs= years.

Table 1, Characteristics of intervention studies